

B.C.P.W.S.A. FALL 2013 Annual General Meeting - MINUTES

-Introductions –Heather Beach, Lindy Thompson, Lorele Houde, Holly Levebre, Alana Taylor, Ray Velestuk, Joan Velestuk, Cheryl Gagge, Paris Yun, Debra Munro, Cindy Thomson, Cindy Armstrong, Irina Radacina, Yvonne Blomer, Bev Ross, Al Young, Sus Szabo, Susan Robinson, Caroline Forsyth, Frances Robinson.

-Spring 2012 Minutes

-Passed by Cheryl Gagne

-Seconded by Cindy Armstrong

-Treasurer's Report (Cheryl Gagne)

- Present balance \$8,143.49

-Donations: \$2,000 BC Hockey Benevolent Association

- \$250 Legion

- \$350 Provincial Health Services Authority

-Current Balance (Gaming Fund) \$60.98

-Membership Fee Reminder (Cheryl Gagne)

- \$25 family membership due by December 31st, 2013

(In order to be a 2014 Membership in good standing)

-Fundraising updates:

- Canucks for Kids Grant Application update (Cheryl Gagne)

BCPWSA had applied but was turned down. But we did receive the Canucks alumni grant.

-Provincial Health Services Grant (Heather Beach)

We applied and received \$350.00 to be used for comforts during support group meetings for parents.

We can also apply for a special one time project grant of \$5,000. Hopefully this grant will grow in the future.

-Legion Grant (Heather Beach).

Heather wrote to Lynn Valley Legion and received a \$250 grant. Suggestion for all of us to write to the Legion in our community. Please email Heather for her example letter if you would like to write to your community Legion.

-Sandoz donation (Mandy Sieban and Heather).

Pharmaceutical companies were asked to sponsor conference. Sandoz paid for the conference coffee breaks \$160.00.

- Skating Party (Cheryl Gagne). Spent \$380.00 and we got \$2,100 come in for donations. Every year this party gets bigger and more successful. Please email Cheryl if you want info on how to go about doing this in your community.

- Wine and Cheese Party and Pub Night (Cindy Thomson) Idea for a fundraiser. Cindy found a pub that is pretty central. Over 50% of funds raised goes to the charity. Pub is the Town Hall Pub by Ikea in Coquitlam. This may be a future idea for a fundraiser.

- Movie Night: (Frances Robinson) Frances interested in doing Clova Movie night with any interested families in the Cloverdale, Surrey area. Please contact Frances if you would like to help out.

-QSP (Heather Beach). Will send out general information for anyone who would like to buy magazines. Facebook promotion would be good. Use this fundraiser for any magazine subscriptions throughout the year. E.g Christmas presents for friends.

-Reports:

☒ FPWR One Small Step Walkathon 2013/2014 – (Cindy Thomson)
-happened in August in Burnaby. Goal is \$1.3 mil. Raised for research in total for all the walks in the various countries and communities..
-\$8,050 raised (with 100% of funds going towards research with the Foundation for Prader-Willi Research) in Burnaby walk.
-Another walk hosted in Ladner raised \$16,000.
--Thank you ladies for supporting Prader-Willi Syndrome Research!

☒ FPWR Conference 2013 (Cindy Thomson)
Reported on this year's conference. Excellent workshop on anxiety. Get a link to speakers and presentations on the FPWR website through the Youtube link.

☒ Cindy announced that she will host a gala for FPWR in 2014. Location in Burnaby on October 3rd, 2014. Also possibility of a conference during that same time period under development.

☒ Rare Disease Network (Mandy Sieben). Amazing group of parents, 3rd Wednesday of every month. Speakers, connection with parents, no fee. BCCH location. Website: rarediseasefoundation.org

☒ Information and Handouts for the studies in Edmonton. Dr Haqq has current study under way and also will start new study in the fall for children with PWS. She will be recruitment soon. Handouts given.

☒ PWS growth chart: Growth Chart information needed for PWS children who is/was not on GH. Even information from the growth period prior to starting GH is needed. Contact Dr Butler to help out with this endeavour.

☒ Book Release (Yvonne Blomer). Yvonne is a writer and Poet and teaches writing. She appears in the book: How to Expect what you're not Expecting. Her story with PWS included in the book. Yvonne had 3 copies for sale.

☒ Spring Meeting Suggestions or Requests: Burnaby location is central. This is a very casual meeting. Suggestions on anyone who would like to add to that agenda or give a short presentation is welcomed.

New Parent Package: Susanne Szabo developed a package to be sent to new diagnosed PWS families. Package will be available on the website and will be distributed in endocrinology clinics.

- BCPWSA – Elections / Appointments
 - President - Heather Beach by acclamation
 - Vice-President – Mandy Young by acclamation
 - Secretary – Frances Robinson by acclamation
 - Treasurer - Cheryl Gagné by acclamation
 - Member at Large – Lindsay O’Hearn by acclamation

-SPRING Meeting DATE – **TBA**
Location Burnaby as per usual

- Adjournment
- Moved to Ray Velestuk.
- Seconded by Parise Yun.

